Living with dementia, interdependence and citizenship

Living with dementia, interdependence and citizenship: Narratives of everyday decision-making

Authors

Keyes, S. E. (Corresponding author: sarah.keyes@ed.ac.uk) ECRED (Edinburgh Centre for Research on the Experience of Dementia), School of Health in Social Science, University of Edinburgh.

Clarke, C.L. ECRED (Edinburgh Centre for Research on the Experience of Dementia), School of Health in Social Science, University of Edinburgh.

Gibb, C.E. Formerly, Faculty of Health and Life Sciences, Northumbria University

Abstract

This paper argues that interdependent relationships are key in realising inclusion and citizenship for people living with dementia. We focus on decision-making as one aspect of everyday life which reflects opportunities and challenges associated with citizenship. Accounts from people living with dementia of everyday decision-making provide insight into strategies for negotiating responsibilities as they shifted with dementia. An inductive, secondary data analysis developed decision narratives from the data of 61 interviews conducted in the UK. The interviews were with 12 people with a diagnosis of dementia plus their nominated care-partner in a qualitative study which focussed on information management and sense of self. The secondary data analysis identified strategies for inclusion, emphasising relational interdependency amidst challenges. The five-stage framework of an Ethic of Care positions this interdependency as a response to barriers to inclusion and citizenship. Interdependency, therefore, emerges as key to realising relational citizenship.

Points of interest

- This paper argues that relationships are key in realising inclusion and citizenship for people living with dementia (people with a diagnosis of dementia and their care partners).
- People often find a sense of belonging in 'everyday' decision-making. This paper presents accounts from people living with dementia about how they approached everyday decision-making and ways in which this had changed with the onset of dementia.
- People living with dementia spoke about finding a negotiated position in relationships, valuing interdependence over dependence or independence.
- We use an Ethic of Care to link this interdependence with ways in which relational citizenship can be realised for people living with dementia.

Introduction

People living with dementia are a marginalised group living with the effects of physical and mental impairment but have not been included significantly in Disability Studies and the Disabled Peoples Movement (Bartlett 2014a; Mental Health Foundation 2015). However, recent developments have raised the profile of people with a diagnosis of dementia as a collective campaigning group, with an increasing number of self-advocates and dementia activists (Bartlett 2014b). This increase in active involvement has been paralleled in the academic literature with developments of understandings of how citizenship can be realised (O'Connor and Nedlund 2016; Birt, Poland, Csipke and Charlesworth 2017). An aspect of these developments has been understandings of narrative citizenship (for example Baldwin and Bradford Dementia Group 2008; Clarke and Bailey 2016) and relational citizenship (for example Kontos et al 2016). These foreground accounts of everyday experiences and interpersonal interaction in realising citizenship in terms of societal participation and, to a lesser extent, critiquing the societal distribution of power and voice that lead to the exclusion

of people living with dementia. Baldwin and Greason (2016) suggest that there are parallels between these developments in Dementia Studies and the Disability and Mental Health Movements.

As well as understanding dementia as an impairment, we position dementia as an experience within which people face barriers to inclusion which impact upon their day-to-day lives. Such barriers include attitudinal and behavioural barriers and barriers that become embedded in institutional and collective practices (Thomas and Milligan 2015). In adopting a social model perspective, we acknowledge the social model of disability as a tool for understanding the experiences of disabled people as opposed to a theory of disability per se (Oliver and Barnes 2012; Thomas and Milligan 2018).

In understanding experiences surrounding disability, the use of terminology in describing people is key (Albrecht, Seelman and Bury 2001). An exploration of how this relates to the experiences of people with a diagnosis of dementia and informal/family carers is outwith the scope of this paper. The focus throughout this work is on experiences which are shared and in the context of relationships, and so we have chosen to use the term 'people living with dementia' to describe people whose lives are directly affected by dementia (either through a diagnosis of dementia or as an immediate/family carer). Where a distinction within care-partnerships is most relevant (including when citing literature which makes a distinction) we refer to a 'person with a diagnosis of dementia' or their 'care-partner'.

Background

Citizenship – the path to interdependence and societal inclusion?

Historically, disabled people have been viewed as second class citizens (Barton 1993). This includes people with a diagnosis of dementia (Brannelly 2011a) who face 'considerable challenges and significant barriers' to maintaining citizenship (Brannelly 2016, 304; see also

Boyle 2014). Recent work in the field of Dementia Studies has drawn upon contemporary Citizenship Studies, highlighting the importance of people living with dementia being considered as citizens. This work has included theoretical and practical explorations of how people with a diagnosis of dementia negotiate a sense of belonging in their day-to-day lives and local communities and ways this might be enhanced (O'Connor and Nedlund 2016; Bartlett 2016).

Bartlett, O'Connor and Mann (2010) define social citizenship for people with a diagnosis of dementia as 'a relationship, practice or status, in which a person with a diagnosis of dementia is entitled to experience freedom from discrimination, and to have the opportunities to grow and participate in life to the fullest extent possible' (37). Bartlett (2014a) highlights the significance of inclusion and citizenship for citizens with dementia since 'dementia threatens one's identity and capacity to be an effective citizen in a socio-cultural and neurological sense' (1292). Citizenship has also been linked with human rights and self-determination (Nedlund and Larsson 2016; Kelly and Innes 2013).

Exploration of everyday experiences to understand inclusion and citizenship is critical because this is where the 'drama' of exclusion (Ward, Campbell and Keady 2016, 396) and inequality exist (Clarke et al 2010; Boyle 2014; Clarke and Bailey 2016). Baldwin and Greason (2016) conceptualise citizenship as a dementia care practice; something that is realised through action and in relationship in everyday lives of people with a diagnosis of dementia. Such practice can have a positive impact (Osterholm and Hyden 2016) and can lead to community inclusion (Phinney et al 2016) and to representative democracy (Sonnicksen and Jared 2016). This citizenship-as-practice in the lives of people with a diagnosis of dementia has also been demonstrated using the arts to challenge dominant tragedy discourses (Dupuis et al 2016) and self-help groups (Orulv 2012). Furthermore, experiences within the 'domestic sphere' and in 'ordinary spaces' (Bartlett 2016, 453) have

been highlighted as significant in developing understandings of citizenship, of people with a diagnosis of dementia, and of their agency in decision-making (Boyle 2014). Narrative citizenship and relational citizenship are of significance to this perspective.

In common with disabled people as a wider group (see Smith and Sparkes 2008), a key aspect of inclusion of people living with dementia is the significance of people's own accounts of their experiences. Foregrounding accounts from people with a diagnosis of dementia about their own experiences has been a tool through which voices have been heard (see Kellett et al 2010; McKeown et al 2010). This foregrounding has been linked with citizenship of people living with dementia (Clarke and Bailey 2016). Baldwin and Bradford Dementia Group (2008) place narrative agency as the starting point for narrative citizenship (being able and having the opportunity to express oneself narratively). By focussing on narratives of everyday decision-making, our work further develops understandings of citizenship in practice, translating experiences of a relatively small number of people living with dementia to understandings of - and potential ways to promote - inclusion and citizenship.

Relational citizenship (defined as 'a model that is premised on the importance of independence, reciprocity, and the support of persons with dementia as active partners in their own care' (Kontos, Miller and Kontos 2017 182-183)) is also central to developing work around citizenship and people living with dementia. It highlights the significance of interpersonal relationships in realising citizenship. Relational citizenship emphasises both the significance of day-to-day relationships for people living with dementia and also the ways in which interpersonal interactions can enable citizenship (Brannelly 2011b; Webb 2017). Indeed, Shakespeare, Zeilig and Mittler (2017) posit that a relational model of dementia lays the basis for a human rights approach to dementia.

In conceptualising interpersonal relationships in the context of living with dementia, an Ethic of Care sets out 'ethical practice upon which good care can be established' (Brannelly 2006, 198). An Ethic of Care posits a framework of five elements. All five elements are present within an 'integrity of care' (Barnes 2012, 19): *Attentiveness:* the care giver recognises need in the care receiver; *Responsibility:* the care giver responds; *Competence:* the care giver provides care; *Responsiveness:* the care receiver responds; *Trust:* is established between care giver and care receiver (Tronto 1993, with trust added by Sevenhuijsen in 1998). An Ethic of Care positions this framework as a 'species activity' (Tronto 1993, 103), and therefore one in which both people with a diagnosis of dementia and their care partners are engaged.

An Ethic of Care brings together the personal and the political: a framework for how care should be carried out on a personal level and the values and political responsibilities underpinning care (Barnes et al 2016). This then leads to 'inclusive citizenship principles' offering 'alternative possibilities for sustaining citizenship' (Brannelly 2016, 304), challenging the dichotomy of dependence and independence (Fine and Glendinning 2005; Gilmour and Brannelly 2010) and advancing the value of an interdependence-based approach which identifies all people as engaged in care-giving as well as care-receiving relationships (Brannelly 2011b; Barnes 2012). Taking an Ethic of Care as a political framework as well as a practical guide, Brannelly (2016) conceptualises three challenges to citizenship and people with dementia that can guide inclusive practice: relationship between individual and state; citizenship as a practice; citizenship as identity and belonging.

Decisions – a specific manifestation of citizenship

The freedom to make autonomous decisions (and the ability to execute those decisions) is a universal aspect of citizenship and all the more so for disabled people who often encounter

barriers to even the most every-day of decisions (Barton 1993). This includes people with a diagnosis of dementia (Boyle 2008). Boyle (2014) and Boyle (2017) define freedom in decision-making for people with a diagnosis of dementia as 'deliberative agency'. The onset of dementia both poses challenges to decision-making processes and provides new things to have to make decisions about, for example care-home placement (e.g. Thein, D'Souza and Sheehan 2011) or advance care planning (e.g. Laakkonen et al 2008). Gooding (2013) positions supported decision-making as a rights-based disability concept and this is evident in relation to living with dementia (e.g. Tyrrell, Genin and Myslinski 2006), end of life (e.g. Goodman et al, 2013), and surrogacy of care-partners in decision-making (e.g. Miller, Witlatch and Lyons 2016).

Fetherstonhaugh, Tarzia and Nay (2013) highlight the importance that people with a diagnosis of dementia place on remaining involved in decisions and the key role of care-partners in enabling decision-making. They identify the difference between 'subtle support' and 'taking over', the importance of 'hanging on' to involvement in decision-making for as long as possible, and the difference between feeling central to the decision-making process and feeling marginalised and excluded from it. The importance of a relational understanding of decision-making is highlighted too in relation to care-partners (Fetherstonhaugh, Rayner and Tarzia 2016), care staff (Fetherstonhaugh et al 2014) and in assessing decision-making in the management of finances (Boyle 2013a).

Relationships between people with a diagnosis of dementia and care-partners are significant in decision-making dynamics, with most couples experiencing a gradual shift towards the care-partner increasingly taking responsibility for decisions (Samsi and Manthorpe 2013). In their comprehensive review of literature relating to the decision-making processes of family care dyads, Miller et al (2016) suggest that the involvement of care-partners in decision-making is essential to the process of translating the values of people with a diagnosis of

dementia into decisions. Alongside this, much of the recent literature emphasises that the involvement of people with a diagnosis of dementia in decision-making should not end with changes in their decision-making abilities (Miller et al 2016). Samsi and Manthorpe (2013, 949-960) suggest a continuum which spans from 'supported decision-making' (in which processes are mutual) through to 'substituted decision-making', in which carers take over decision-making, drawing upon 'retrospective knowledge' of a person with a diagnosis of dementia, and the 'best interests' principle to make decisions.

In summary, the concept of citizenship and people living with dementia brings together contemporary debate in the fields of Dementia Studies, Disability Studies and Citizenship Studies. Focussing on narratives of people living with dementia and their day-to-day relationships provides insight into citizenship. Specifically, an Ethic of Care provides a framework that challenges barriers to inclusion and citizenship. The analysis reported in this article aims to describe and analyse how the experiences of everyday decisions and decision-making provide an example of day-to-day life through which the tensions surrounding the involvement of people living with dementia can be explored and through which fresh understandings of citizenship emerge.

Methods

This secondary data analysis study analysed data that was collected as part of larger UK-based project, known as 'Give and Take: Information Use and Self-Management in Dementia Care', which aimed to examine ways in which people living with dementia manage information about themselves and dementia. The 'Give and Take' study adopted a post-structuralist methodology, defined as 'a theory, or group of theories, concerning the relationship between human beings, the world, and the practice of making and reproducing

meanings' (Belsey 2002, 5). Data were collected through face-to-face interviews, as the researchers sought to gain an understanding of the mechanisms used to access and disseminate knowledge, the content of knowledge assimilated and disseminated and use of information in day-to-day life. Research questions concerned the way in which people spoke of their lives and how this is influenced by the content and form of such knowledge as well as the influence of knowledge management on partnership with service providers and the influence of the research process itself on the way that people spoke of their lives (Knapik 2006).

The research was approved by an NHS Research Ethics Committee (Reference 08/H0907/85) and included only those with the capacity to provide informed consent, as determined by their Responsible Medical Officer (RMO) (UK Mental Capacity Act 2005).

All participants were service users and their care-partners at one of two participating day hospitals in the North East of England. Approximately 350 people who had been diagnosed with dementia in the previous three to twelve months formed the recruitment pool. A sampling matrix was developed within which anonymised details were mapped against criteria that are likely to influence access to, understanding of, and use of, different forms of knowledge (e.g. Morgan and Trouth 2013): (1) time since diagnosis (2) other pathologies (3) pattern of service provision (4) social support structures (5) socio-economic profile (6) employment status (7) age (8) gender (9) educational profile. This sampling matrix was used to identify a pool of potential participants to ensure breadth of representation across the criteria. 30 people were identified as potential participants from this pool and were approached, in the first instance by their RMO. Of these, 16 consented to participate and each of these nominated a care-partner (a family member or close friend) to also participate in the research. People who were considered by their RMO as lacking capacity to consent and people with additional communication impairments (e.g. severe sight and hearing loss) were

considered to be outwith the scope of the study. These are limitations of this study which impacted upon the diversity of participants and consequently upon the extent to which our work represents decision-making amongst the wider population of people living with dementia.

Informed consent was viewed as a process within the context of the relationship between researchers and people taking part and was revisited throughout the research. Interviews followed the guidance identified by Clarke and Keady (2002) as crucial in data collection with people with a diagnosis of dementia: sufficient engagement to allow confirmation of issues raised (seeking consistency over time for an individual rather than 'checking' for accuracy with dementia by a care-partner); a mutually trusting relationship; a collaborative approach; minimising anxiety and tiredness ; augmentation of data collection; emotional engagement by the researcher; and detailed attention to reliable data recording. Everyone was provided with contact details for the local Alzheimer's Society branch should they wish to discuss their experiences and service needs and were encouraged to contact their GP or memory clinic if they had concerns about their welfare.

Interviews with these 16 people with a diagnosis of dementia and their care-partners took place on up to three occasions. This allowed for a research relationship to develop and for people to pace the interviews to suit their energy levels (Clarke and Keady 2002). All the of the people with a diagnosis of dementia who took part were living in their own home. People chose the location of interviews and chose whether they were interviewed alone or with their care-partner. Our imperative to not disrupt the relationship between the person with a diagnosis of dementia and care-partner, and our respect for their chosen way of engaging with the research took precedence over any inclination we had to interview people separately; this is consistent with much social science research in Dementia Studies (e.g. Jurgens et al 2013).

Altogether, 69 interviews took place. The first interview with each person or couple explored personal biography, the information about dementia they had received, and what they wanted others to know about themselves and their dementia. The second interview sought to identify areas of day-to day-life where there was tension with others, and returned to the questions on information use. The third interview asked people to describe themselves in relation to decision-making and responsibilities and ways in which this had changed with dementia. These interview schedules were developed from our previous research into the 'contested territories of everyday living' for people living with dementia (Clarke et al 2010).

Secondary Data Analysis

The secondary data analysis focussed on data from the third interview: decision-making and responsibilities and ways in which this had changed. This selection was based on the depth of insight into interpersonal interaction in everyday life in this aspect of the data. As these two interview questions were also the most complex, the data is from 12 of the couples/families. In the other four cases, adherence to the criteria identified by Clarke and Keady (2002) meant that the interviewer had used their discretion and not asked those questions. Consequently, the data analysed is drawn from those with mild/moderate dementia and further reflects the continuing from research exclusion of those more affected by dementia.

The secondary data analysis began with transcripts of 61 interviews with 12 people with a diagnosis of dementia and their nominated care-partner. Eight people with a diagnosis of dementia chose to be interviewed on their own and in these cases their care-partner was also interviewed separately. Two people with a diagnosis of dementia chose to be interviewed jointly with their care-partner for all three interviews. The other two people with a diagnosis

of dementia, chose the combination of some interviews on their own and some joint with care-partner.

Key to the secondary data analysis was the development of 'decision narratives'. These were accounts from people living with dementia on (1) how things used to be (2) how things are now and (3) areas of tension or disagreement. Throughout the analysis a 'decision' was considered to be 'any account of interpersonal interaction which had led to a change of course (of action, thought or relationship) in any aspect of everyday life'. The demonstration of agency (deliberative and/or creative) within any interpersonal interaction also indicated that a decision had taken place.

There were eight stages to the inductive secondary data analysis, with the tools of NVivo10 (a Computer Assisted Qualitative Data Analysis Software tool) used throughout:

1. An initial reading of a selection of transcripts and mapping out of areas of interest in the data.
2. Analytical focus on responses to the research questions concerning decisions.
3. Extraction of data concerning decisions.
4. Appraisal of the data that had been extracted, highlighting the narrative of each unit of analysis (the care relationship with its constituent individuals - person with a diagnosis of dementia and care-partner). Data for each couple or family was formed into a decision narrative – drawing out (1) how things used to be (2) how things are now and (3) areas of tension or disagreement.
5. Tabulation of decision narratives. This was done so that the individual narrative of couples or family was considered in the context of others' narratives.
6. Development of a thematic coding framework. This framework was structured around change (extent and impact); strategies for inclusion; interdependency; control and

involvement; and responsibility (burden and familiarity). From this coding framework, an overarching narrative that represented the care relationship was identified. The extent and impact of shifting responsibilities, the strategies for inclusion which people had developed, the significance of interpersonal interaction and challenges associated with shifts in responsibilities were key to this narrative.

7. Return to decision narrative from each couple or family. This was done to check that the messages in the data for each were preserved in the presentation of data.
8. Return to the original 61 transcripts from the 12 people with dementia and care-partners. This was done as a strategy to locate the analysis within the data set as a whole and identifying the relationship with the five stages of the Ethic of Care framework: *attentiveness* (or caring about); *responsibility* (or taking care of); *competency* (or care giving); *responsiveness* (or care receiving); and *trust*. (Tronto 1993; Sevenhuijsen 1998). Evidence of any element of the Ethic of Care framework was identified and links between the elements mapped out.

Findings

In keeping with our commitment to social model disability research, the findings are presented in a way that is deliberative about privileging the voices within the decision narratives. All names are pseudonyms.

Shifting responsibilities

People described how, with the onset of dementia, the practical and relational dynamics of everyday decision-making had changed. The extent of these changes varied, as did their impact. Examples given included day-to-day decisions (such as what food to buy) as well as decisions about wider issues (such as finances). There were changes in who made decisions and how decisions were made, which led to shifts in responsibilities.

Margaret and John Williams spoke about how John, husband and care-partner, had previously struggled to boil a kettle and how, as Margaret's dementia had progressed, he had needed to take oversight of (*responsibility* for) cooking:

> Margaret, wife and person with a diagnosis of dementia: Yeah, well he generally does the dinner. But I go in and help him, just the same. So it's, you know… I mean, I used to do everything like that in any case. Because I used to cook everything but… Well, I do – I mean, he helps a lot. He looks after us. But I still do the work – you know, the cleaning, just the same. Just the same.

Maria Robson, wife and care-partner, described how, in the past, she and her husband Leslie, a person with a diagnosis of dementia, had usually shared and managed decisions and responsibilities in ways which reflected each of their 'domains' (referred to by Leslie himself as 'spheres of influence'). This sharing had been both practical and relational, with *attentiveness* to each other's skills, experiences, strengths and limitations:

> Maria, care-partner: Anything that was specifically his domain, he would do. Or things that were specifically of my domain I would decide. Anything that was joint, we would decide jointly.

Maria went on to describe changes that had come with dementia. The locus of decision-making had shifted, but the importance of sharing what could be shared remained:

> Maria, care-partner: I'm more inclined to say, for example, 'it looks best if we do such and such. Is that okay with you?' So I've arrived at a point of view as I will put it to Leslie and ask for agreement rather than us doing it in a more equal way.

Maria reflected upon how these shifts in *responsibilities* had occurred:

> Maria, care-partner: I think it's been a gradual, evolving …since the problem has developed…I think it was probably beginning to happen even before we knew… before we had the Alzheimer's definitely diagnosed.

As a daughter and care-partner, Julie Smith referred to lots of changes that had taken place. These changes meant that she was taking on *responsibilities* that she had never had before:

> Julie, care-partner: I've never dealt with the finances of the house. Mother has always done. Paid all of the bills … but that's a worry because I don't know what I'm going to do, because I just don't understand finances at all but I think I may have to get help with that later. Or maybe my sister could give me advice over the phone.

Strategies for inclusion

In the context of shifting responsibilities, people had developed strategies for inclusion. For example, Ron Taylor, husband and care-partner, spoke about organising things so that Jilly, his wife, a person with a diagnosis of dementia, maintained as much involvement as possible:

> Ron, care-partner: I get her to help me and that. I don't just ---You know, she helps me. But I like to know what we are going to have and organise everything. And then she goes shopping with me and it's not … She's still involved; I try and I keep her involved, you know. Because I don't think it's a good thing not to get involved.

Later in the interview, Ron reflected on the situation:

> Ron, care-partner: I mean to say it's not a case of like taking over her work, it's a case of, like, necessity, really. I mean to say I would prefer her to do lots of things if she could, like. But sometimes the consequences aren't worth it, you know.

Eve Atkinson, wife and care-partner, described a strategy for inclusion whereby she sought to support Frank, husband and person with a diagnosis of dementia, in deciding about something that affected him:

> Eve, care-partner: If it's things concerning him I try to get him involved and make a decision himself. For instance, like, we had someone here from Social Services, who's offered him a place to go for a day a week. You know, not just sitting around. I don't want him to go anywhere here he's just, you know, sitting around among similar people … So I asked him 'well, how do you feel about this?'… he made the decision and said he will go and try it out.

In negotiating a shared *responsibility* amidst these shifts, a tension emerged in which it was important that care-partners did not take over too much control. Julie Smith, daughter and

care-partner to Suzanne Smith, spoke about the tension in ensuring that her mother's involvement continued, speaking about one aspect of household life:

> Julie, care-partner: I don't know whether she said anything or not – but we've actually got help in the house, now, on a Friday … Mum didn't want her to come at first, because she doesn't like other people in the house. But she's settled now and she's got used to the routine … and [the cleaner] does a good job, and she just gets on with it, you know, she always says 'would you like this done, or would you like that done?' … And sometimes I say to mother 'shall we get her to do the kitchen today?' and Mum says 'yes, we'll do that' you know, so there is co-operation between the two of us there.

The five-stages of an Ethic of Care are evident in Julie's narrative above. She was *attentive* to the impact which having a cleaner around the house would have on her mother at the same time as recognising that they needed extra support. She took *responsibility*, both in having a cleaner and in negotiating arrangements in a way that was sensitive to her mother's reluctance to have help. *Competence* was demonstrated in the arrangements which Julie made. These arrangements were sensitive to her mother's reluctance. In her eventual engaging with the new cleaner, her mother was *responsive. Trust* was illustrated in 'co-operation between the two of us'.

Ethel Swift, wife and care-partner, illustrates an approach to continuing to include Ross, her husband and person with a diagnosis of dementia, at the same time as taking on more *responsibility*:

> Ethel, care-partner: Last time that Ross went to the doctors on his own I sent him with a note. So that he wouldn't forget. But what tickled me pink was that doctor sent a note back. Beautifully done – you know, 1, 2 and 3. And I thought, 'Well that's it. Nobody can disorganise it now'. You know, we're all happy. That's excellent.

In this scenario, both Ethel and the doctor were *attentive* to the support needed for Ross to maintain autonomy in his visit to the doctor, and both demonstrate *responsibility* and *competence* in writing or replying to the note. Ross was *responsive* in engaging with the process, leading to *trust* between the three.

Interdependency

People described how they valued interdependence in their interactions. That is, they neither valued the care-partner taking over full responsibility for everything nor the person with a diagnosis of dementia having total independence. The decision narratives valued relationships and the role of interpersonal interaction.

For Margaret Williams, wife and person with a diagnosis of dementia, decisions of day-to-day life were a partnership in which she continued to be involved:

> Interviewer: Well if you get up this morning – who decides what you're going to do today? Do you say, 'Oh, I fancy doing something'?
>
> Margaret, person with a diagnosis of dementia: No, not really, we just… Together we just say we will go out and see something and then ... I'll do the cleaning and that ….and he does the food. He does them now. I used to always do it, but he's taken

> over because sometimes I used to forget things and … But otherwise I can do all the cleaning and all the things like that.

Jessica Charlton, daughter and care-partner, spoke about a time when her mother was very independent. Jessica explained that this had shifted:

> Jessica, care-partner: She knew she was having trouble in her own mind, in making these decisions and maybe making decisions and finding that they were the wrong decisions and in the end worrying about the future and future decisions. So yeah, it was a worry and it was a worry she could switch once she could say 'right, I'll just phone [son]'.

Jessica also spoke of shared *responsibilities* with her sister. Above, Julie Smith also spoke about sharing responsibilities with wider family. In these cases, it was interdependency with other family members which enabled inclusion. For example, Ethel Swift, as a wife and care-partner, spoke about the role of wider communities and networks, for example the way in which her solicitor got in touch to say that the Enduring Power of Attorney was going to change:

> Ethel, care-partner: But we're surrounded, really, by a sort of good network…. But it's not every solicitor that would write to you with that kind of things. But that's an example of the kind of network that we're surrounded by.

In a further example, Beth Dodds, daughter and care-partner, describes the tensions in involvement and the partnership from her perspective:

> Beth, care-partner: Yeah, I mean I would never sort of do anything – make a decision about something if she didn't know about it. I mean, sometimes she might forget about it, you know, But I mean, if something cropped up, even before the decision was made I would sort of speak to my sister…

The following quotation from Ethel Swift, wife and care-partner, highlights ways in which a strategy for inclusion (writing things down on the calendar) needs to be backed up with interpersonal support:

> Ethel, care-partner: So he can still do it on his own, but I suppose, yes, there's an extra responsibility there. And there's more responsibilities in reminding him. It's written down on the calendar and he looks every day, but he still has to be reminded.

Brian Edwards, a person with a diagnosis of dementia, reflected upon the extent to which his relationship with his wife and sons was characterised by interdependence. He reminds us that there is knowledge about a person with a diagnosis of dementia that only the person themselves has, and that others need to remain *attentive* to this knowledge. Within a focus on give-and-take in relationships, what becomes significant here is the focus on shared decision-making, but in the context of the person with a diagnosis of dementia having knowledge about themselves that only they have:

> Brian, a person with a diagnosis of dementia: There's got to be two views, but it's me that knows what I can do. Other people don't know what I can, you know. And they may make their – make a decision and they may have an opinion, but it doesn't mean that I haven't got to do it because they've said so, if I think that I can do it …Not that I'm wanting to get into a situation where I would be saying 'Oh yeah, I can do it' but I

can't do it. You know, that would be silly, you know. And there would be a problem if it ever became that way. But at the present moment in time, no I don't…

Brian drew from his experience in order to make sense of his current situation:

Brian, a person with a diagnosis of dementia: No, that's the way I've always gone about things. You know, as I say, talk to each other. When I was in industry, I talked to everybody. I got them to understand what I wanted to do. Listened to what they had to say, and then we would move forward…Because they were involved, right, then we all moved forward in the same direction. But if you didn't talk to them, right? Well it's a tad fragmented, isn't it?

Jean Dodds, mother and person with a diagnosis of dementia, had spoken about her life in which she had had a lot of responsibility. She then spoke about the current situation and the impact that her dementia had on interactions with her daughter, her main carer:

Jean, person with a diagnosis of dementia: And just leave them to it. There's no argument, no nothing. I just let them do it, don't I?

Interviewer: So you're happy to do that?

Jean: Uh-huh. My mind doesn't carry me that far.

Maria Robson, the wife and care-partner who we heard from at the beginning of this findings section, describes decision-making in the context of a mutually respectful relationship:

Maria, care-partner: I suppose in any kind of decision-making… I was going to say as a matter of courtesy you want to include the other person if it's going to affect them.

> And in the nature of the relationship, we support each other and so you would not want to have been, shall we say, riding roughshod over the other person. And so, yes, I would do things to include Leslie and make decisions mutual in as far as possible. Yes, I wouldn't want him to feel excluded or belittled or marginalised. I think it's important for self-esteem and so forth. And for the sake of the relationship.

Leslie Robson, Maria's husband, talked about the complexities of involvement and interdependence from the perspective of a person with a diagnosis of dementia:

> Leslie, a person with a diagnosis of dementia: I suppose it's very variable. And if one is dealing with things about oneself, it's usually fairly straightforward as to what you want to do. If others are involved, of course, the more you have family members or whatever it might be, then it's spreading the net rather and you're having to take into account what other people need. Their needs or what they want or…

Amidst the interdependence within decision-making outlined above, there were areas of tension and disagreement. Exploring these challenges provides further insight into ways in which people negotiated a sense of belonging in day-to-day life.

Challenges of shifting responsibilities

Within the decision narratives, people had encountered challenges amidst shifts in responsibilities. In the following quotation, Tony Johnson reflected on the extent to which things had changed, and upon the responsibility these changes had placed on his wife, and upon his desire to continue a role within their relationship:

> Tony, husband and person with a diagnosis of dementia: I don't get frustrated easily. I never have. The only concern is whether it's too much pressure on Gill [wife] and I know that she does feel the pressure, the responsibility more than before. But basically, as I say, it's not a worry. It's not a worry to me. Somehow or other I've got to keep trying to take responsibility for other things that I should be responsible for. She's got to sit on my shoulder like my mother used to. So its…it's always, as always a shared responsibility. And we do communicate pretty well, but she worries a lot more than I do. But that's always been the case.

In a separate interview, Gill Johnson, Tony's wife and care-partner, articulated her perspective:

> Gill, care-partner: Well, yes, that has changed dramatically in that we always discussed things before. We always shared. And now I feel the responsibility for everything in our lives, more or less, is on my shoulders. And I resent that. I've been trying to decide what feeling it was, I get frustrated, but I do resent that fact that everything has been …I mean, Tony is quite happy to do things when I ask him. He doesn't always do them … but it's not because he won't, it's he forgets…And even if he does them, I've still got to check up and see that it's been done. I can't rely on him and that is very sad.

Eve Atkinson, wife and carer partner of Frank, talks about a situation where there has been a lot of change and in which she perceives little involvement of Frank, though note (above) that Eve had elsewhere given an example of a decision in which she had involved Frank:

> Eve, care-partner: Well I suppose we've always sort of talked about things and decided together. And now he's not really capable of making any decisions, you know. About anything – the house or anything – I've got to make the decision to go ahead and do things, or you know, he doesn't even think about things that would have been his prerogative in the past. I mean, a lot of things he would have just said 'Oh, look at that'. You know, it needs repairing – he would get the things and do it. But now, you know, he doesn't notice the thing that's wrong.

For most of the couples and families, there was a tension, a balance needed in who had control over what aspects of everyday life. Annie Charlton spoke about how she feels about this:

> Interviewer: So do you feel that's hard – that you've had to, kind of, give over your decision-making to other people? Or do you just feel like it's a natural progression?
>
> Annie, a person with a diagnosis of dementia: Yeah, I don't care for it. But I know I have to put up with it. No, there's lots of times I'm thinking 'Oh, I should have been doing that'. And you're frightened in case they're going to take too much over and not leave you anything.

This 'taking over too much' could be understood as potentially lacking *attentiveness*, which would lead to Annie being dependent on her daughters. Anna Edwards, wife and care-partner, spoke about her struggles to include Brian:

> Anna, care-partner: I do talk to him about it, but I do feel at times that I don't always confer with him. I go ahead and do things because it's quicker to do it that way. And

> then I feel guilty about it afterwards. That he should still be involved with the process. And I'll sort of take responsibility of making sure that the bills are paid. And I do talk about it to him. I do feel guilty at times that maybe I'm not giving him a chance to be more involved because I just feel it's better for me to do it. But that might just be me. And he may feel pushed out of it at times, I don't know.

The overarching narrative presented above tells a story in which the onset of dementia had brought with it shifting responsibilities and dynamics relating to decision-making. In the context of these shifts, people living with dementia had adopted and developed strategies which purposefully ensured that people with a diagnosis of dementia remained included. Relationships were highly significant to the narrative, with a value placed on interdependence. The narrative speaks of challenges associated with shifting responsibilities, demonstrating the complexities of everyday decision-making for people living with dementia.

Discussion

The decision narratives, constructed through the process of secondary data analysis outlined above, recount ways in which decisions that had always been part of life remained part of life with onset of dementia. At the same time, dementia brought with it decisions which people had not previously encountered. The onset of dementia had led to some areas of decision-making becoming more complicated, as they became more challenging. Responsibility was a significant aspect of the decision narratives as shifts in who made decisions led to responsibilities being redefined and boundaries redrawn. The changes and challenges of the onset of dementia meant that there were shifts in decision-making processes in order that all aspects of life and living remained attended to. People spoke mainly about household decisions as opposed to areas such as advance care planning and end of life issues identified in the background section. The significance of *responsibility* within the decision narratives

links the interpersonal interaction surrounding everyday decision making with an Ethic of Care framework.

Strategies had been developed so that people with a diagnosis of dementia remained included in the day-to-day running of the household. As identified in the literature (Miller et al 2016; Fetherstonhaugh et al 2013; Samsi and Manthorpe 2013), the role of care-partners in enabling involvement of people with a diagnosis of dementia was significant. There are echoes of Fetherstonhaugh et al (2014)'s strategies for inclusion (simplicity, knowing the person and negotiation). For some, stability came from involvement that was based on a familiarity of responsibility, for example remaining involved in household tasks. At times, in order for involvement to be maintained, responsibilities had shifted. Some care-partners spoke about areas of decision-making within the household that had not been their responsibility prior to the onset of dementia, or areas which had once been shared responsibility becoming their sole responsibility. The narratives also refer to decisions relating to finances. Some care-partners spoke about challenges as their responsibility for finances increased, and for some handling finances was totally new.

In the decision narratives, continued inclusion was important, both for people with a diagnosis of dementia and for care-partners. The significance of relationships in maintaining a mutuality of responsibility seems key to that inclusion, as did an emphasis on 'subtle support' as opposed to 'taking over' (Fetherstonhaugh et al 2013, 146). This illustrates Boyle (2013b) and Fetherstonhaugh et al's (2016) emphasis on a relational approach to decision-making. The continuum of involvement identified by Samsi and Manthorpe (2013), outlined in the background section, is also evident: instances ranged from supported decision-making, where processes were neutral, through to substituted decision-making in which carer partners drove the process, albeit drawing on retrospective knowledge of a person with dementia. At times, this meant that care partners took on more responsibility but made sure that people

with a diagnosis of dementia remained informed, and consulted as much as they felt was possible, about decisions. Many of the strategies which people had developed were rooted in interdependent relationships of mutuality and reciprocity (valuing neither independence nor dependence) and inclusion was a process in which interdependence was continually redefined. None of the care-partners or people with a diagnosis of dementia expressed a view that they should take complete control of decisions and responsibilities and most were seeking to work out the tensions relationally. Interdependency conceptualised in this way relates to theoretical understandings of interdependency within an Ethic of Care.

From the perspective of the people living with dementia, inclusion in everyday decision-making was enabled through the role of interdependent relationships underpinned by the five practical stages of an Ethic of Care framework (Tronto 1993; Sevenhuijsen in 2003). These interdependent relationships were an enabling factor in negotiating day-to-day decision-making and responsibility. An Ethic of Care positions such relationships as a political response to inequality (Barnes 2012). Hence, our understanding of the significance of interdependence in decision-making demonstrates a response to disabling barriers to citizenship which people living with dementia encounter. It demonstrates an understanding of citizenship in 'ordinary places' and the 'domestic sphere' (Bartlett 2016, 454). It identifies ways in which people living with dementia make sense of themselves, their value and worth through everyday interactions with those around them.

Returning to Kontos et al's (2017) definition of relational citizenship, our findings shed further light on the importance of reciprocity and people with dementia as active partners in their own care. Our focus on interdependence challenges the place of independence in Kontos et al's definition, though it could also be argued that the interdependence between people with a diagnosis of dementia and care-partners was maintaining independence for them as a couple and/or family. Broadening the discussion out to consider citizenship, our work also

highlights the significance of interdependent relationships in enabling citizenship. In particular, the three challenges to citizenship which Brannelly (2016) identifies can be considered in relation to decision-making, and the enabling role of interdependent relationships which are identified in the findings of this study. Firstly, in thinking about citizenship as a relationship between each person living with dementia and state, an approach which adopts the principles of an Ethic of Care in facilitating participation and involvement, would break down barriers to citizenship. Secondly, in understanding citizenship as a practice, interdependence in decision-making challenges notions of choice and control being about individual citizens. Thirdly, our work also highlights the significance of interdependent relationships in the context of decision-making in creating a sense of identity and belonging.

The theory around inclusion and citizenship within this research bridges the gap between dementia and Disability Studies identified in our introduction. Defining disability for people living with dementia as a set of physical, environmental, psycho-emotional, and attitudinal barriers, there is evidence in our work for the role of interdependent interaction, as conceptualised within an Ethic of Care, in breaking down those barriers. This reinforces our positioning of people living with dementia as disabled people. Broadening this out, the role of interdependent relationships in the inclusion of disabled people as a wider group is evident. The work demonstrates that interdependent relationships can break down barriers to citizenship for disabled people, and that a disabled person who is engaged with others in this way will be experiencing more meaningful citizenship.

Limitations of the study

As with all research that is grounded in a social model approach to understanding the experiences of disabled people, it is important to define the boundaries within which this process is emancipatory. In addition to the limitation of diversity of sample outlined in the

methods section, limitations of this work include those associated with a secondary analysis of data: the data was not primarily collected for the purpose of exploring everyday decision-making, meaning that there may be insights not captured in the data we have been working with; the methodology of the original study (post-structuralism) was determined prior to the secondary data analysis, though it was selected because of its attention to societal and interpersonal power dynamics and thus compatibility with a social model approach; there was no scope in the process of the analysis to return to those who had taken part in the initial study to sound out ideas and develop emerging themes with their input. A further limitation which impacts on the scope of our findings is that the research exclusively recruited people with a diagnosis of dementia who were able to identify a care-partner (spouse or family member) to take part in the research alongside them.

Conclusion

Our work began with people who are living with dementia and their accounts of everyday decisions and decision-making processes. These accounts were developed into narratives through a process of secondary data analysis. These narratives provided insight into interdependence in the context of shifting responsibilities.

Amidst shifts in responsibility, people had developed strategies which enabled inclusion in decision-making processes. Whilst these strategies were unique for each couple and/or family, the overriding message was that interdependent relationships remained key in negotiating new ways of living and being and the associated decision-making in achieving this.

An understanding of relational citizenship becomes evident as one in which citizenship is realised through interdependent relationships. Considering citizenship as a relationship between people living with dementia and the state, the implications of our work are that

interdependent relationships are a significantly enabling factor. When citizenship is understood as a practice, interdependent relationships become significant in the decision-making associated with enabling choice and control. Identity and belonging, leading to enhanced citizenship, can also be enabled through interdependent relationships.

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